

**Summary of
OASIS Focus Group Discussions
Spring 2007**

State of Indiana

Family Social Services Administration

Division of Disability and Rehabilitative Services

Prepared by Briljent, LLC and Davis Deshaies, LLC

INTRODUCTION

The State of Indiana Division of Disability and Rehabilitative Services (DDRS)/ Bureau of Developmental Disabilities Services (BDDS) is exploring changes in the way people and families receive services. Specifically, the BDDS is developing an objective assessment process and a way to allocate resources that better match what each person needs. This initiative is called 'OASIS' which stands for the '*Objective Assessment System for Individual Supports*'. The goal of OASIS is to create a uniform funding approach to determine fair and equitable levels of state support. This level of support will be based on an objective assessment and driven by the principles of Person Centered Planning (PCP) and measurable Individualized Support Plan (ISP) outcomes. To accomplish this, the 'objective assessment' tool being used is the Inventory for Client and Agency Planning (ICAP), which will be conducted by Arbitre Consulting, Inc. The 'system for individual supports' is a resource determination tool and an interactive budget tool, which will be developed by Davis Deshaies, LLC. An important goal in the planning, development, and implementation of OASIS includes a significant dialogue with consumers and their families.

Ten focus group meetings were conducted by to gather the initial response and feedback of consumers and their families in regard to their current level of services and future needs. There were 52 total attendees with 34 consumers either present or represented by parents or guardians. The focus group meetings were held between the dates of March 19, 2007 through April 17, 2007. Cities were selected across the state of Indiana in all eight Bureau of Developmental Disabilities Services (BDDS) districts including:

- Fort Wayne
- Muncie
- Gary
- South Bend
- Bloomington
- Indianapolis
- Evansville
- Seymour

The findings of the focus groups conducted reflect the experiences of the consumers, guardians, and providers that attended. These experiences are

unique to each case although there were a number of points of commonality—recurring themes that were comments and concerns echoed frequently enough to be considered representative experiences.

RESULTS

Much of the data collected and time spent in the focus groups was based upon providing an opportunity for the attendees to communicate their experiences and thoughts freely, without the constraints of a rigid format. Responses were not required and although most attendees chose to take advantage of the opportunity to participate in the discussion, some did not respond to every focus group question asked of the group. Additionally, the second meeting held in Bloomington did not follow the same format of questions; the meeting focused specifically on consumer and family concerns. The focus group facilitators collected data that was in most cases subjective and narrative although the attendees themselves shared demographic information which can be directly expressed as detailed on the next page:

Aggregate demographic information for OASIS focus groups	
Number of consumers living at home	20
Number of consumers living in group homes	14
Number of consumers who are minors	9
Number of consumers with jobs	13
Number of consumers in school	11
Number of consumers that feel safe	30
Number of consumers that fear injury	4
Number of consumers who are healthy	32
Number of consumers who are not healthy	2
Number of consumers who live in stable homes	30
Number of consumers who want to move	4
Total number of primary consumers in attendance	10
Total number of secondary consumers in attendance (parents/guardians)	35
Total number of other care givers or family in attendance	7
Total number of participants	52

SHARED EXPERIENCES

A number of common experiences were discovered during the open discussion of the focus groups. Detailed as case studies below, the experiences are notable as thematic issues shared by the majority of primary and secondary consumers.

Case #1— The need for access to transportation

A family in attendance had two children with cerebral palsy, both of whom live at home. They feel they receive the majority of care that they require, but have had major disruptions in their ability to meet their transportation needs. The public transportation system in their area provides an inadequate coverage area and has limited points of access and limited routes. The system also charges four times the standard rate to transport disabled persons. Due to these factors, the family must rely heavily on their own vehicle for transportation. Their vehicle however, is aging and has an out-dated lift system that is in constant need of repair.

Access to adequate transportation has been identified as a common concern among consumers and a fundamental problem for the majority of focus group participants.

Case #2—The demands of caring for those needing constant care

One of the focus group participants is a guardian who cares for an individual with a severe case of autism that requires constant attention and care. The responsibility of care had been split between the parent in the evening and direct care staff during the day, which was tenable and had worked for a while. Unfortunately, due to the high demands required by the consumer's condition, the parent lost their full-time job. The family has been feeling increasingly isolated from friends and extended family. They found most of their acquaintances, family, and friends were unsure and uncomfortable in dealing with a severely disabled person. The interaction or lack thereof, has been so

difficult that they simply stopped trying to interact with others. Their problems were only compounded with the stress of losing their income.

Consumers that require a significant amount of attention (especially constant 24 hours a day, seven days a week monitoring) can place extremely difficult requirements on care providers. Some guardians feel isolated in their lives and homes because of the complex and consuming demands placed upon them. Addressing this fundamental concern has been identified as a priority issue, especially for secondary consumers during the focus groups.

Case #3—The concerns of aging parents with consumers

With the average age of the population rising as baby-boomers get older, many adult children are now caring for their parents in greater numbers than ever before. Many live in their own home with their aging or elderly parents or in the parents' home. One family that attended a focus group has this situation in reverse. They have an adult child who has lived with them for her entire life. She was raised in an era before waivers and community based services for the disabled existed, and her parents kept her at home because they did not consider institutionalization as an acceptable option. They have always cared for all of her needs. She has less demanding physical needs than some consumers, but still requires significant care and attention. They have no other relatives who are willing to care for their adult daughter when they are gone, and this has been a cause of increasing stress and fear as the parents become elderly—requiring care and assistance themselves.

Almost all families related this as a fundamental concern: “Who will care for my loved one when I am no longer able?”

Case #4—Concerns caused by high staff turnover

Staff turnover and the retention of qualified staff is a concern in any organization. In the discussions with focus group participants, obtaining and maintaining good direct care staff is a primary concern with utmost priority. Many group participants felt that inadequate wages and benefits result in not retaining the best qualified and trained direct care staff. Consumers would like to see the same staff on a continuing basis rather than face the task of constant retraining, and forming new bonds with their caregivers. Becoming comfortable with new staff is stressful for most consumers and their families.

One family experienced an unusually high percentage of staff turnover that has resulted in constant retraining and added worry that their child is not being cared for properly. They purchased a house for their middle-aged child to live in with around the clock direct care staff supervision. This arrangement has allowed their child to live in the house for a number of years with staff, but the staff changes have upset him and caused a great deal of distress. His parents have received phone calls from their son's neighbors that he is wandering around the neighborhood unattended. This creates added stress in his parents' lives and they fear for his physical well-being. Staff turnover has also led to their son becoming more introverted. Maladaptive behaviors from their son have also increased, and he no longer cooperates with staff or participates in group activities.

Staff turnover and consistency of care is a fundamental concern for most, if not all, of the primary and secondary consumers participating in the groups.

Case #5—The need for supported employment opportunities

There are many consumers who are willing and capable of participating in the workforce, but not all have an opportunity to prove themselves capable or have the access to jobs that allow them to earn wages. One of the participants has been on the waiver for a number of years and graduated from high school in the recent past. His parent applied for and requested different kinds of supported

employment, but there was very limited assistance provided in their area for this need. Earning one's own wages can provide a sense of purpose and self-fulfillment. Unfortunately, this consumer is currently spending nearly all of his time at home with his parent, who tries to entertain him. This is at the expense of time lost for obtaining valuable life and social skills that could be gained outside the home through supported employment.

Participants agreed that this type of service should be more readily available to consumers. Even if they function at a higher capacity than others, they still need assistance in their lives. They may not require constant attention or physical supports, but they still desire to participate in their communities and work as other citizens do.

Case #6—The need for flexible use of allocated resources

Many participants shared frustrations regarding the method of reducing hours for the following year based upon actual usage in the previous year. Several expressed concern that the system penalized people who would try to use hours honestly, wisely and frugally. Frustration was expressed regarding the inability to use resources on a seasonal or cyclical basis when the services are most needed. There are a number of families with school-age consumers whose required direct care staff hours vary seasonally based on the school year. During the school year they will require fewer hours because their consumer's care is being provided by Department of Education employees, but during the summer months they will require more direct care hours. One family in particular worries about the number of hours they will receive every year. They try to use their hours as efficiently as possible, but if they do not use enough hours during the school year, they fear their overall hour allotment for the following year will decrease. This leaves them with shortened summer resources and increased work and frustration. People are forced to use services when they are not most needed in order to have them when they are needed, or face losing hours. Participants indicated that they would like their annual hourly allotments to be more flexible and adapt to their seasonal or cyclical needs.

Case #7—The need for adequate case manager resources

Most consumers and their families are aware of IPMG as the sole case managing entity. However, a nearly unanimous response from attendees indicated that families are not satisfied with the number of case manager hours spent with their consumer. Consumers perceive that there has been a significant increase in the volume of case manager assignments. Many shared that they felt their case managers worked hard, but were responsible for such a high number of cases it was not possible for them to adequately stay current with each case's status. Others shared frustration and concern in regard to the lack of quality communication from the state, case managers, and providers.

One of the consumers related during a meeting that they were a few months overdue for their yearly assessment and meeting. They also have yet to speak with their new case manager. He and his family are concerned that there is not enough focus on the individual consumer's goals and needs from the newly-appointed case managers. Even if there is enough care and concern, they feel that there are not nearly enough hours to focus on individual cases because of the perceived drastic increase in case loads per case manager.

Families realize that case managers are now expected to be less of an advocate for specific individuals, but consumers are concerned that they will not receive the attention they deserve and require.

Case #8—The need for access to eligible services

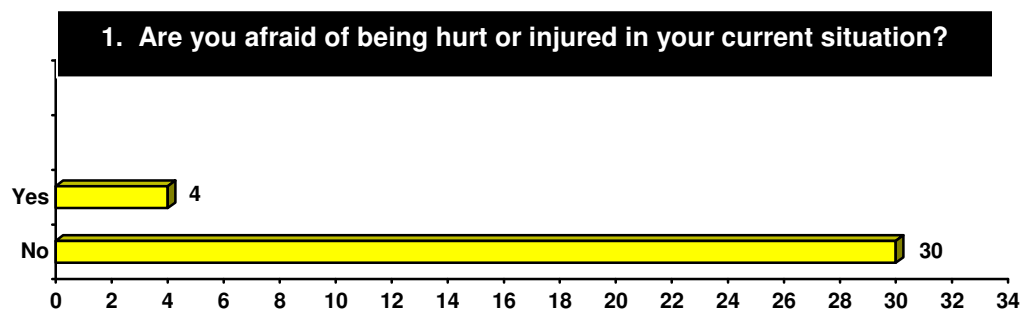
Several stories shared included instances of consumers not being able to receive services for which they are eligible. Many noted that not all services are available in all geographic regions. This forces extra time requirements and transportation expenses, or the services are forfeited. One consumer explained that he lives at home with his family in a mostly rural area and has an allocation for speech therapy. There are no speech therapists currently working in his immediate area, and he does not have the means to travel frequently to receive this service. The funds allocated for his speech therapy have been revoked. He did not use them;

therefore he did not continue to receive the allocation for this service. He and his family very much want these services, but are unsure how they can participate in them.

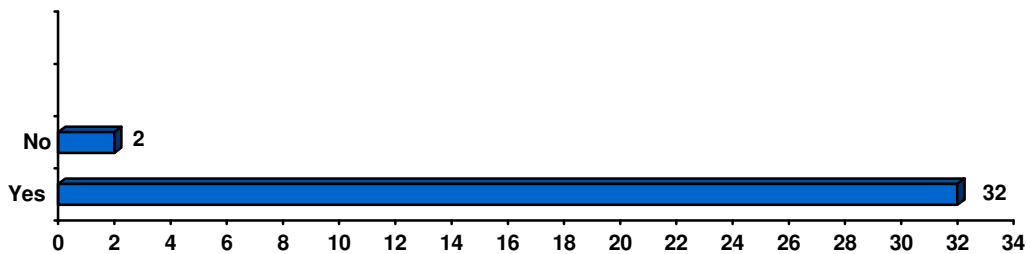
Consumers either want these therapies available in their area, the means provided to transport them to the therapist's location, or an allowance of funds to allow the consumer to budget their own travel to the therapist's location.

PERSONAL OUTCOMES

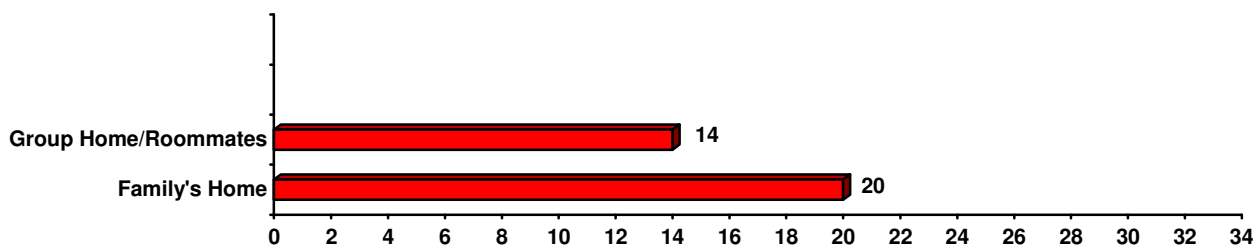
Personal outcomes are what people expect from the services and supports they receive. Summarized below are direct responses from the primary and secondary consumers to the focus questions asked that could be measured. Responses were encouraged from every attendee but not mandated and some primary and secondary consumers declined to take the opportunity to have their answers recorded.



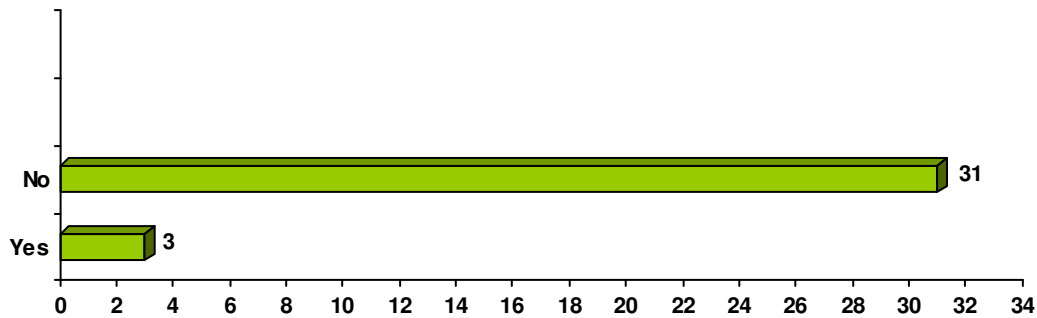
One consumer in particular was purportedly in imminent danger due to neglect from direct care staff. Other parents that expressed concern had children with extremely physically-demanding conditions and felt that the direct care staff was ill-trained or ill-suited to care for their children.

2. Do you believe that you are healthy?

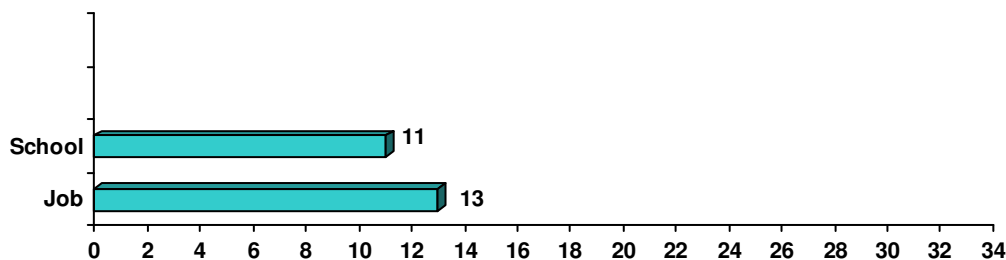
Nearly all consumers and/or parents and guardians felt that they were healthy and received adequate health care. One consumer indicating that they believe they are unhealthy is the same suffering purported neglect.

3. Where do you live?

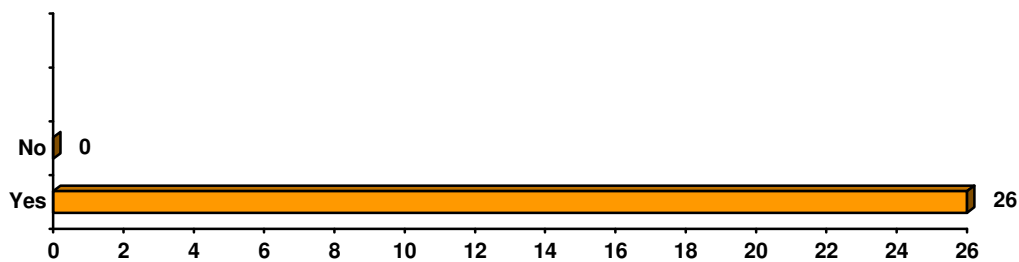
The Group Home/Roommates category encompasses all consumers who responded that do not currently live with their family or guardian. In the Family's Home category, some of these consumers are minors. They and their family members are hopeful that they will have the opportunity to live more independently of their families in the future.

4. Are your family and friends satisfied with your level of service and support?

There were only a few families that expressed complete satisfaction. The majority desired some manner of change in the waiver system and therefore could not be classified as satisfied. Their issues are noted in this report.

5. Do you currently have a job or attend school?

All of the consumers and families interviewed were of various ages which accounts for the number of consumers not in school and/or without a job. Some of the consumers are minors and cannot have a job; whereas others are past school age and/or of retirement age. Some consumers are not able to attend school or have a job.

6. Are you involved in the development of your Person Centered Plan?

All consumers and/or their families were involved in the initial writing of their Person Centered Plan. Most, however feel that their plan is either ineffectual or not fully implemented to their satisfaction.

OTHER COMMON ISSUES IDENTIFIED

The following issues are also noted as common responses from focus group participants across the state.

1. Concern was expressed regarding the quality of trained staff. Many felt that their staff often lacked the proper qualifications or training needed to adequately care for consumers. Several shared that many workers seemed to have a low commitment to the success of consumers' setting and achieving goals. They perceived that the job was often treated with a clock-in and clock-out mentality. Workers lacked the attention to long term progress, and often times only engage on a very superficial interaction. Again, this situation was attributed to low compensation and low standards for staff employment. Even when staff is properly trained, the retraining process has to be completed frequently due to high staff turnover. Retraining is time consuming and frustrating for families. Unqualified or disinterested direct care staff can pose a safety issue and are an added and unnecessary worry for already complicated lives. "Will my loved one be safe and free from harm?" and "Will my loved one be happy with the direct care staff that serves them?" are primary concerns of families and guardians.

2. Concern was expressed about the inefficiency within the current system that prohibits using allocated resources for a consumer for reasonable services that are not specified within their plan. Consumers and their families would really like to have more control over how the resources allocated to them are distributed between services. Additionally, strong desire was expressed to have the ability to have more choice in the selection of providers.
3. Concern was expressed regarding the potential for fraud by providers due to the lack of accountability in paper work. Some participants shared examples of hours billed for services that the consumer never received.
4. Concern was expressed regarding the requirement to use Medicaid approved contractors for modifications to homes and vehicles. Many felt that this system required them to use higher cost quotes and lower quality of work than if they could have multiple contractors bid on a contract. More than one story of negative outcomes suffered by consumers and their families due to contractor issues was shared in the discussions.
5. Concern was expressed regarding the perceived unfairness of limiting resources to families that choose to keep their loved ones at home in comparison to those placed in other homes. People that choose to take the responsibility of caring for their consumer want the ability to receive the same level of service that would be available if they did not keep their loved one at home.

6. Concern was expressed regarding the lack of emergency support and care for consumers. Many felt very insecure about what would happen to consumers who were living at home in the event of family crisis. Although some provided examples of case managers or staff who had helped find solutions, they felt that these individual efforts were the exception, not the norm, and no system was in place to adequately address this need.
7. Concern was expressed in regard to the inefficiency of a system that does not provide a mindset of investing resources earlier in a consumer's life that would reduce necessary services and dependencies later in the consumer's life. If funds could be allocated earlier, then significant individual progress could lead to better quality of life, increased capabilities and independence.
8. Concern was expressed in regard to accessibility of meaningful activities for consumers. Consumers and/or their families felt that engaging in meaningful activities provides an indispensable component of a consumer's daily life.
9. Concern was expressed in regard to the volume of those on the waiting list for waivers, as well as the length of time for those on the waiting list. Waiver services are indispensable to those who are receiving them and people recognize their impact. Participants also felt that many people go without or wait too long to get on the list because of lack of knowledge or communication about the program and services that they are qualified to receive.

10. Concern was expressed regarding consumer's current and future living accommodations. What if the consumer wants to move into their own home, or what if they just need increased assistance at home? A lot of parents and guardians worry that there will not be enough funding or service support in the future, if and when their consumer chooses to move into their own home. Not all consumers will be able to live on their own, but there should be options for those that desire roommates or around the clock direct care staff.
11. Concern was expressed in regards to the method used to set provider rates. Participants were not completely aware of how provider and service rates were set. They felt that there was too great a variation in rates among the different districts. "How do I know if my services are being set at a fair rate?"
12. Concern was expressed in regard to exercising more choice and personal decision making power regarding their money and services. They would like to have more input in how their allocated funds are spent. Some would even like to be able to choose varying levels of services and choose what services they feel that they need. Consumers would like to have more control over their own lives.

NEXT STEPS

The focus group meetings were one of the initial components of the OASIS project communication plan. The feedback received helped to identify concerns and issues that are most significant to consumers and their families. This information will be considered as the OASIS project begins a pilot in BDDS District 4. Additional meetings with consumers, families, providers, and other stakeholders will continue throughout the life of the project. It is important to the success of the project to keep an open dialogue of communication between all parties. Additional project information may be accessed by the following methods:

OASIS-ICAP Help Lines: (317) 234-5222 or 1-888-527-0008

Email: OASIS-ICAPhlep@fssa.in.gov

Website: <http://davisdeshaies.com/page10.html>